

A System-Change and Community-Based Participatory Research Approach to Understanding the Role of Informal Social Networks During the Cancer Care Journey



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Background

- Racial disparities in quality and completion of cancer treatment have been associated with poorer health outcomes among Blacks compared to Whites
- Support from friends and family during the cancer journey is critical. Given the known differences in cancer experiences and outcomes by race, differences in family & friend experiences by patient race may exist as well
- Little research examines family and friend involvement from a system-change perspective, which highlights how racial differences in transparency and accountability (i.e., structural racism) can prevent equitable treatment

Research Questions

- How are informal social network members (i.e., friends and family) involved in the survivor's cancer journey? What is the impact of cancer on this network?
- To what extent is network member involvement or survivor perceptions about impact of cancer on the network associated with specific attributes or characteristics of the cancer system?
- Are there similarities or differences by race?

ACCURE Study

Accountability for Cancer Care through Undoing Racism and Equity (ACCURE)

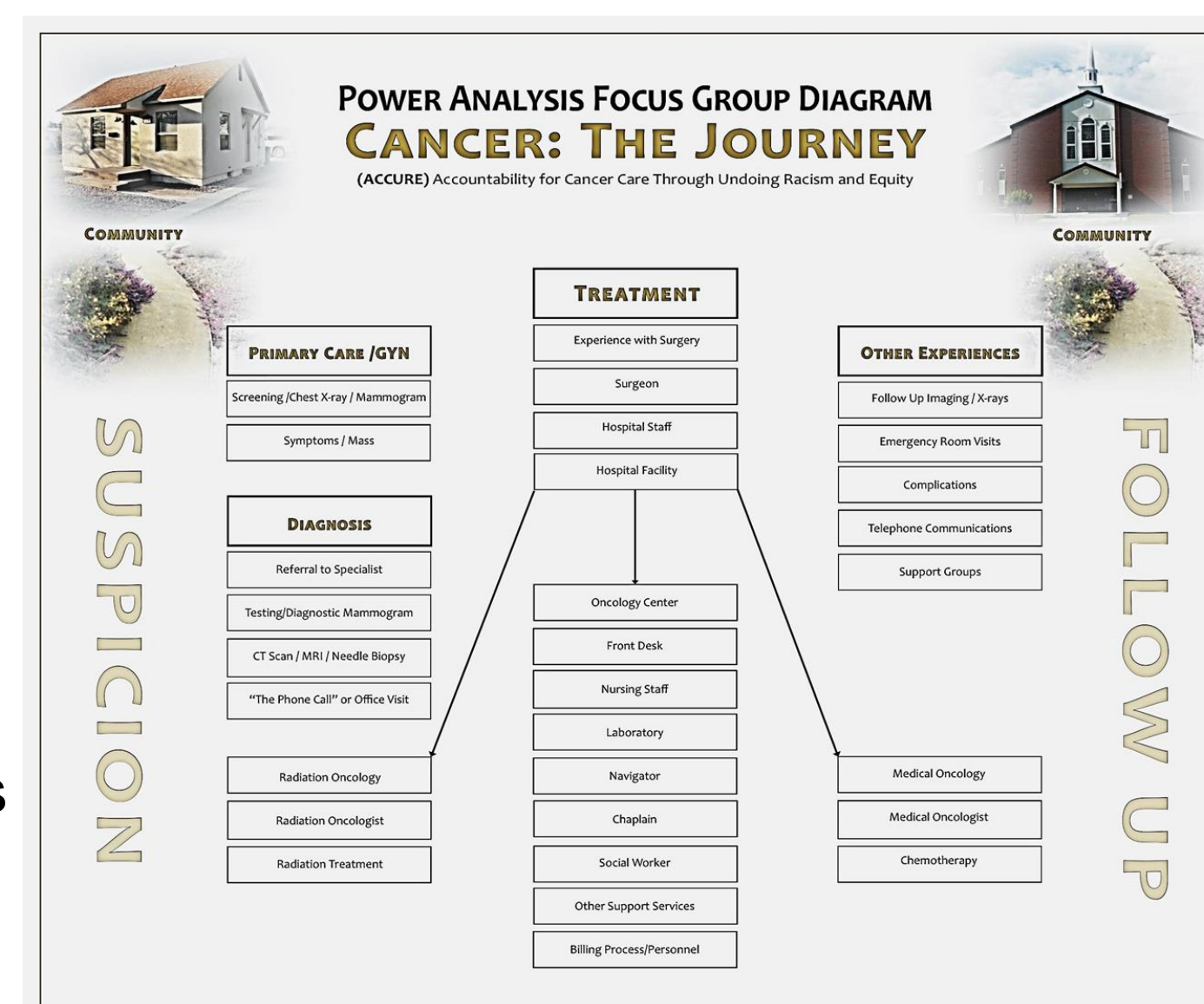
- A 5-year, NCI-funded systems-change intervention addressing disparities in treatment initiation and completion and outcomes for early-stage Black and White breast and lung cancer patients
- Uses a community-based participatory research (CBPR) approach, guided by a diverse partnership involving academic researchers, a nonprofit community-based organization, a community coalition, and providers and staff from two cancer centers



Greensboro Health Disparities Collaborative
Greensboro, NC

Methods

- Formative work for ACCURE
- Secondary qualitative analysis of focus group data
- Focus group power analysis of "pressure points" in cancer care
- Community-academic coding pairs: 1) read transcripts independently; 2) read again with focused, guided questions and assigned codes 3) shared answers to guided questions; 4) reached consensus on assigned codes
- Thematic analysis with phenomenological approach led by KRE, with feedback from coding pairs and community partners



Study Sample

Cancer survivor profile by race, cancer type, and institution

	Cancer Type	Cone Health Cancer Center (Regional Hospital)	University of Pittsburgh Medical Center (Teaching Hospital)
Black	Lung	3	1
	Breast	4	4
White	Lung	5	1
	Breast	5	4



- Participant Eligibility:** Completion of treatment for stage 1 or 2 breast or lung cancer at the participating cancer centers in the previous 12 months
- Focus Group Composition:**
 - Stratified by race and cancer type
 - Race of participants and lead facilitator matched; co-facilitator was opposite race of participants

Themes

Illustrative Quotes

Social Network History of Cancer Influenced Survivor Experiences

"...when my sister died I felt a lump as I was preparing for her funeral, and so my thing was not even deal with any of it. But I called and when I called I have to say the ball started rolling and that. And I still said no for a good while." **Black breast cancer survivor**

"I have had...very close friends that listened to the medical professionals about...and they died horrible lives. Because [the providers said] 'Oh well we can do this...We'll change the formula for the chemo. That'll take care of it.' Well, no it didn't...That's why I told my doctor...I make a decision that's the way it's gonna go one way or another." **White lung cancer survivor**

Patient-Provider Communication Was Affected by the Presence of Friends or Family during Medical Appointments

"I didn't like [how my doctor was talking to me]...and just not hearing me talk or anything...I had my son come [from out of state] and my son came and he went in and talked to the doctor, and uh...explained to him the type of person I am and that and I have to say he changed...it's been a year...I have to say he's different now. You know, if he's more concerned he, he will stand there for a minute now and talk." **Black breast cancer survivor**

Support for Managing Pain and Side-Effects from Treatment Often Provided by Friends and Family, Rather than Medical Providers

"I wish someone had talked to me after the surgery. I could not get out of bed. My husband could not help. I would have liked to know. I had to borrow front closing shirts. I wish I had heard about what would happen after." **White breast cancer survivor**

"It has been a problem for me...the side effects...that's when I was thinking about quittin' cause another guy, one of my friends, he was talking about stopping and he had [colon cancer surgery]...side effects is hard." **Black lung cancer survivor**

Support for Families was Inconsistently Provided by the Cancer Care System

"I didn't have no income coming in, and they had put me out from where I lived...I was homeless. [The social worker] was saying she can't help me...and never returned my calls until the doctor got on her...My girlfriend opened her arms to me and I was staying there with her." **Black breast cancer survivor**

"He was very kind to my family, he was extremely kind to my husband, who really needed somebody to sit down and talk to him, and he did, and my son, also." **White breast cancer survivor**

Support from Friends and Family with Professional Health Care Backgrounds Was Particularly Helpful

"My wife is fairly forceful...She was my interpreter...I'm married to a medical person and it helps, you know cause, you know when you go through this thing, you learn a whole new language." **White lung cancer survivor**

"I was married to an oncologist so I had a little bit of a head start in terms of knowledge of breast cancer and the curability of breast cancer so that gave me a very positive attitude." **White breast cancer survivor**

Results

Black Survivors:

- More pointed in connecting their cancer journey to lingering emotional distress and grief from cancer deaths among friends and family
- To a greater degree than their White counterparts, discussed learning about side-effects (e.g., what to expect, how to manage) from friends and family as opposed to health care providers
- Discussed friend and family assistance with asking questions, clarifying information, and improving patient-provider communication as particularly important

White Survivors:

- More likely to discuss having friends or family with medical experience to call on for advice and support. This support led to feelings of increased preparedness, and more confidence in treatment decision-making and the adequacy of care provided
- Unlike Blacks, did not describe economic consequences of their cancer journey for their family
- Discussed provider attention to emotional distress among family during visits

Black & White Survivors:

- Described a need for better education for their support network about side-effects and symptom management
- Reported positive cancer-related experiences among network members that were a source of encouragement and influenced where they received care
- Family and friend support was critical after treatment ended and "safety net" of care disappeared
- Lack of support because of small informal social networks, often due to friend and family living in other places, was an issue for some survivors. These survivors described loneliness and a lack of support to deal with the emotional and practical challenges of their cancer journeys

Conclusions

- Friends and family helped to address problems with treatment and care, improve transparency (e.g., clarify jargon, communication problems), and encourage patient treatment initiation and completion
- Racial differences in network involvement are likely influenced by unequal access to resources and opportunities (e.g., more education and professional medical experience among social networks of White survivors) and can influence the type of help provided
- Opportunities exist to improve the support provided to the family and friends to manage their own emotional distress and assist with patient's physical & psychosocial challenges
- Routine psychosocial health and needs assessments could help to better identify patients and loved ones who need support for grief, economic issues, and emotional distress, increasing accountability for addressing these issues
- Intentional partnerships between cancer centers and community groups could improve survivor and family member access to resources and support during treatment and after treatment ends

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